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SECOND EDITION

Disability Across the Developmental Lifespan

AN INTRODUCTION FOR THE HELPING PROFESSIONS

JULIE SMART

Disability Across the Developmental Lifespan

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Preface

Two acronyms used throughout this book should be defined. IWD(s) is individual(s) with disabilities, and IWOD(s) is individual(s) without disabilities. These acronyms are used for clarity and are very distinct, clear-cut dichotomies, and there are difficulties in using dichotomies to describe any type of identity. Nonetheless, as an introduction to the discussion of disability and the individuals who experience disabilities, the choice of these acronyms favors clarity, while sacrificing some accuracy and precision. Also, IWD and IWOD use "person-first" language, specifically, "an individual with a disability," rather than a "disabled individual."

To my knowledge, there is no book that considers the experience of disability in relation to theories of human growth and development. Freud, Erikson, Maslow, and Bandura never included IWDs in their theory development or in their research. On the other hand, the so-called "clinical" or "allied health" academic disciplines of medicine, nursing, physical therapy, occupational therapy, and rehabilitation counseling give little, if any, thought to stages of human development, concentrating solely on diagnoses and the resulting medical and rehabilitation treatment plans. In addition, the general counseling and psychology academic disciplines, and their textbooks, consider psychiatric disabilities and mental retardation, but not the developmental experiences and tasks of individuals with these disabilities. Unfortunately, the fields of psychology and counseling rarely include the experience of physical disabilities in their training.

The result is that the social, developmental experiences of IWDs are not addressed in the university curricula. This may appear to be a broad, damning judgment. However, this lack of attention to the social, developmental experiences of IWDs (and their families) has been long-standing, persisting for centuries. The disciplines of human growth and development, psychology, and counseling focus on the "normal," or, better stated, a narrow, illogical definition of normal, and the clinical and allied health disciplines have focused on the medical model of disability in which attention was directed toward *only* the physical, biological, and medical needs of the individual. Certainly, there was no intentional malfeasance in ignoring IWDs in academic curricula or in physicians focusing solely on medical needs. Both were acting on the mandate given to them by the larger society. Nonetheless, university graduates have little academic training in disability, and physicians often do not conceptualize IWDs as individuals negotiating developmental stages and tasks.

In contrast, most IWDs, after medical stabilization, think of themselves as normal, ordinary people with the same types of needs, emotions, goals, and developmental tasks as everyone else. The difficulty lies in persuading IWODs to think of IWDs as typical, ordinary individuals. An ethical guideline found in all professions is the injunction to practice within the scope of one's training, education, and experience. Therefore, if IWDs are to be offered developmentally and socially appropriate services (in addition to the necessary medical care), it will be essential

that university curricula include the experiences and needs of IWDs. Academicians, researchers, theorists, and scholars fall prey to the tendencies of the broader culture to sensationalize, exaggerate, and pathologize IWDs.

In some ways, the absence of IWDs in academic disciplines and the corresponding lack of professional services mirror that of other groups, such as women of all races and ethnicities, LBGTQ individuals, and those of racial and ethnic minority groups. Indeed, throughout this book, we shall learn that effective criticisms were leveled at the developmental theories for failing to incorporate the experiences of individuals who were not White, middle-class, straight men. This is not to suggest that White, middle-class, straight men were not worthy of study and research, only that there were other groups *also* worthy of study. Nonetheless, there are some differences between these other "disadvantaged" groups and IWDs. First, disability, until recently, was relatively rare. For millennia in medicine, the two-outcome paradigm of total cure or death dominated. Second, IWDs have been isolated, segregated, and institutionalized throughout history. In the United States, IWDs were not given their civil rights, protection under the law, and the right to a quality of life until 1990, long after other groups were enfranchised.

Obviously, the inclusion of IWDs into the social sciences and the addition of the social experiences of IWDs into the clinical disciplines will require an examination of the definitions of "normality" and "humanity." Defining and operationalizing these concepts are not a boring semantic exercise for a graduate seminar; instead, examining long-held assumptions often leads to an understanding that faulty definitions have resulted in the type of daily, lived life of IWDs and, in some extreme cases, whether they lived or died. Most academicians and textbook writers initiate the study of disability by defining disability. In contrast, a more fruitful discussion would result if the consideration of disability began with defining humanity and normality.

Almost one fifth of the American population has some sort of government-recognized disability. However, this statistic is based on the broadest possible definition of disability. Each government agency defines disability somewhat differently, and therefore, the numbers of IWDs vary, depending on the source. The broadest government definition of disability is the Americans with Disabilities Act, which includes a large number of disabilities and, in addition, states that an individual who is *perceived* to have a disability is protected under the law. Furthermore, many would be surprised to learn that such conditions as arthritis, depression, and other chronic illnesses are defined as disabilities. Most individuals with congenital disabilities or disabilities acquired in childhood live into adulthood; many become elderly individuals with disabilities. In spite of this fact, there are no textbooks that discuss the developmental stages of individuals with disabilities throughout their lifespan.

In this book, we first review some of the basic, general aspects of theories of human growth and development. We consider great demographic shifts juxtaposed with this view of development theories. These demographic changes were predicted; however, both the pace and the extent of these changes surprised demographers. One demographic change that is not typically discussed is the rapidly increasing numbers of IWDs and the appraisal of these increasing numbers as progress, both for the individual and for the society. Briefly stated, for many of these individuals, the alternative to living with a disability would be death. The two-outcome model of medicine has progressed to a three-outcome paradigm—death, total cure, or

long-term care of IWDs or individuals with disabilities and chronic illnesses. The combination of medical, scientific, and technological advances and better public health has resulted in more IWDs (and fewer deaths). In the past, disabilities, and the people who experienced disabilities, might have been thought to be failures of the medical professions. Today, the rising number of disabilities is viewed as medicine successes.

PART I

Chapter 1, Understanding Disability, outlines some basic concepts of disabilities, providing only introductory information. Chapter 2 , Basic Principles of Devleopmental Theories and Demographic Changes, discusses the general components of developmental theories, and Chapter 3, Major Demographic Changes and Ways in Which Disabilities Interact With Stages of Development, presents large demographic changes that have changed society and individual experiences and have led to the creation of new medical and helping professions.

PART II

Part II includes six chapters in which the basic stages of life are presented, typically two stages to a single chapter. Included in these chapters are the typical developmental tasks, a discussion of the ways in which demographic and historical changes have affected these life stages, a brief outline of three or four disabilities that are common to these stages of life, and a consideration of the ways in which the experience of disability affects passage through these particular life stages. The inclusion of three or four disabilities in the chapters on the life stages is not to suggest that these disabilities occur only in one or two life stages, but rather to show that the typical age of onset or diagnosis coincides with life stages presented in the chapters. Obviously, the exception is congenital disabilities, or disabilities that are present at birth; their time of onset occurs at a single life stage, birth. Nonetheless, individuals with congenital disabilities negotiate all the succeeding life stages. Note: The preferred term is "congenital disabilities" rather than the negative, pathologizing term of "birth defects."

In this second edition, three new components have been added: The Family and Disability; Cultural, Developmental Stages and Disability; and Intersectionality and Disability. Intersectionality refers to the experiences of individuals when they experience prejudice or discrimination from more than one source, such as an IWD who is African American, or elderly, or a woman, or all of these identities. Nonetheless, it is emphasized that society typically considers an individual's disability to be the individual's "master status," while other identities and role functions are ignored.

There are several sections at the end of each chapter, presented with the intention to provide further learning experiences and to allow students to engage more fully in the information presented. It is hoped that students will be able to integrate the material in the textbook, class discussion, additional readings, and topics of personal interest. Students are not expected to complete all of these exercises, but rather to choose one or two. These sections include "Key Terms," "Videos to View," "Learning Activities," and "Writing Exercises." It is hoped that students will use the exercises to individualize their learning experiences. For example, students in

the allied health fields may wish to learn more about developmental theories, while students in counseling, psychology, and human growth and development will wish to apply their knowledge of the developmental stages and tasks to the experience of disability. These activities may be completed individually or as a group. Obviously, I think writing exercises are important, not only as a practice of a highly critical skill, but also as a way to clarify one's thinking to oneself.

Finally, I use many first-person accounts because these short excerpts illustrate concepts and, furthermore, it is important to understand the experience of IWDs themselves. I am grateful to these authors for allowing me to use their experiences. Occasionally, I have used the same excerpt in two or three chapters because these particular accounts illustrate two or three important points. I simply thought that rewriting the excerpt would be easier for readers, rather than referring readers back to previous chapters.

I have attempted to write about these development theories in a way that is congruent with the intent of the theorists, and I have also endeavored to write about disability from the perspective of IWDs and their families.

Julie Smart

Disability and Developmental Stages: Introduction

Every time we buy a greeting card, we see several aisles of many different types of cards. Most of these greeting cards are written and illustrated examples of socially sanctioned developmental stages. These cards encourage or console those who are beginning new developmental stages and congratulate those who have completed an important developmental stage. Birthdays, graduations, wedding anniversaries, retirement, and widowhood are all considered to be socially sanctioned developmental stages. We would not find a card for significant changes in an individual's life that are not socially approved, such as "Hope you enjoy prison!"

In addition to greeting cards, there are parties, gifts, special food, and, occasionally, distinctive clothing such as wedding gowns, graduation robes, or military uniforms. Elaborate and expensive preparations are part of moving an individual from one developmental stage to the next. Gifts are given, such as at baby showers; family and friends travel great distances to attend ceremonies, all in order to help the individual assume new roles. At times, the individual changes his or her name or gains a new title, reflecting a major shift in identity, both self-identity and the way in which others view the individual. Rites of passage are often part of one's religious/spiritual belief system and signal that the individual has achieved adult status in church or synagogue. Additionally, these developmental stages require individuals to assume new tasks and relinquish other tasks. Birthday parties may also be considered rites of passage, communicating to children that more mature behavior is expected. All of these rites of passage serve to connect individuals to the larger society, and especially in young children, these rites help them find their place in the world and assist in self-definition (Austrian, 2001).

An unusual example of a very common rite of passage involves the Tooth Fairy. Children begin to replace their deciduous teeth (or baby teeth) with permanent teeth between the ages of 6 and 12. In the United States, when small children lose a baby tooth, they place the tooth under their pillow, and then, during the night, while they are sleeping, a mythical figure, the Tooth Fairy, takes the tooth and leaves money under the pillow. In Europe, up until the beginning of the 20th century, it was common to bury the baby teeth. One author described the process of losing a baby tooth as "most unusual."

> The entire process, from the tooth loosening until it actually falls out, is most unusual. It is initially difficult to imagine [for the child] part of the human body becoming so fragile that it ultimately disconnects itself. Children

> will very likely have parted with hair and certainly with nails by the time they lose their first tooth, but deliberately, as part of normal grooming and self-care. Teeth are the only part of the anatomy designed to fall out naturally and then grow back. Once the tooth is out, the lure is not over. (Austrian, 2001, p. 76)

This continued "lure" has led to the creation of the Tooth Fairy. These traditions could be considered rites of passage because the Tooth Fairy, a uniquely American phenomenon, is communicating to children that they are growing up and also assists children to relinquish part of their "baby" identity. Of course, the parents could take the tooth and give the child a quarter, but the loss (of babyhood) and the challenge (of growing up) are eased by the idea of a loving, kind, and mysterious fairy who is ever mindful of the number of teeth of every child. At no other time in life when we lose teeth, such as having our wisdom teeth extracted, do we expect a visit from the Tooth Fairy, perhaps because the loss of teeth is no longer considered to be a change of identity. Of course, when we lose teeth as adults, most of us have given up the idea of the Tooth Fairy. Austrian considered this dichotomy between losing baby teeth in childhood and losing teeth later in life.

> Later in life, problems with teeth represent aging, the body's decline.… Throughout life, teeth remain something that connects adults to their early development—in this loss, in their symbolism, and in the memories provoked each time they see a child from this age period with missing teeth. (Austrian, 2001, p. 77)

Most socially approved rites of passage are considered to be a sign of positive growth, development, and progress. However, there are some predictable, socially approved developmental stages and rites of passage that are not thought to be positive, such as death of a loved one. Instead of parties, balloons, and cake, there are funerals, casseroles, and flowers. The death of a loved one is not hidden; others learn about the death by reading the obituary in the newspaper. Death of a loved one, especially a spouse, is a widely acknowledged (and somewhat predictable) stage of life.

The "Hope You Enjoy Prison" card may appear funny; nonetheless, when an individual is incarcerated, both the individual and his or her family experience "disenfranchised grief." There are no flowers, casseroles, ceremonies, or parties. Going to prison requires a major change in self-identity and disengaging from many relationships and tasks and undertaking new relationships and tasks. Therefore, in some ways, going to prison can be considered a developmental task; however, it is not considered a developmental task because there are very few individuals who actually go to prison and, more importantly, it is antisocial behavior that results in imprisonment. Going to prison is not a predictable developmental stage. There are very few parents who look at their infant and consider that he or she might one day go to prison.

There is no greeting card for the acquisition of a disability, or the birth of a baby with a congenital disability. The onset of a disability, especially at a young age, is not a socially sanctioned developmental task. Nonetheless, acquiring a disability, being born with a disability, or having a disability diagnosed can be considered a developmental stage that requires a change in identity and tasks to be completed. Additionally, simply because most other developmental stages have widespread social approval and the acquisition of a disability does not, the individual (and his or

her family) who experiences disability must, at best, encounter denial or, at worse, prejudice and discrimination. To those who do not have a disability, disability may appear to be pathology, deviance, and inferiority when, in fact, disability is none of these. Indeed, disability is very "normative" and "natural" in the sense that disabilities are very common and a part of the human experience. Nearly one fifth of the American population has a disability, according to the U.S. Census. Nearly 1 in 16 newborn infants has a congenital disability. While it is true that parents never wish for their baby to be born with a disability and no adult ever wants to acquire a disability, most IWDs or parents of infants with disabilities state that disability is not an unbearable tragedy; most report that they return to a "new normality," and some relate that there are positive aspects to the disability experience.

When an individual acquires a traumatic disability or receives a diagnosis of a disability or experiences the first symptoms of a psychiatric disability, he or she often retains a strong, detailed memory of when life changed, often termed a "flashbulb memory." The time of day or night, the exact circumstances such as the color of the blanket when a patient awakes from a therapeutic surgical amputation, the place in which the accident occurred, or the exact moment when the diagnosis of a chronic illness is rendered divides the individual's life into two—before the disability and after the disability. Many IWDs have a party every year to observe the day their disability occurred, such as "Come to the Day I Broke My Neck Party!" They invite friends and family members and have balloons, party hats, cake, and ice cream.

We discuss disability as a developmental task at greater length and in much more detail, including an overview chapter on the basic aspects of developmental theories; the remainder of this book focuses on the integration of disability concepts and developmental theories, and stages of the lifespan.

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PART I

DISABILITY AND DEMOGRAPHICS

CHAPTER 1

Understanding Disability

Chapter 1 defines and describes all types of disabilities, including physical, cognitive, and psychiatric disabilities. These three broad categories of disabilities are based on symptoms, rather than causes. Chronic illnesses are government-recognized disabilities. The six causes for the increase in the number of individuals with disabilities (IWDs) are explained. These six causes are: advances in neonatal medicine; advances in emergency medicine; the longer lifespans for everyone; the longer lifespans of IWDs; more accurate counting; and liberalization and expansion of the definition of disability. Almost one fifth of the American population has a disability, and a congenital disability occurs in one in 16 births.

INTRODUCTION

Two acronyms used throughout this book should be defined. IWD is individual(s) with disabilities and IWOD(s) is individual(s) without disabilities. These acronyms are used for clarity and are very distinct, clear-cut dichotomies, but there are difficulties in using dichotomies to describe any type of identity. Nonetheless, as an introduction to the discussion of disability and the individuals who experience disabilities, the choice of these acronyms favors clarity, while sacrificing some accuracy and precision. Also, IWD and IWOD use "person-first" language, specifically, "an individual with a disability," rather than a "disabled individual."

The purpose of this chapter is to promote a basic understanding of the broad scope of disability. Obviously, the definitions, listing, and categorization of disabilities provided here are only a minimal, broad overview of disabilities. However, before embarking upon the clinical definitions of disability, two important social aspects will be discussed, including:

- The unwarranted fear that IWDs provoke in IWODs
- "People meet my disability before they meet me."

Defining disability is complex and is not limited to the medical and biological aspects of the condition (Barnes, Mercer, & Shakespeare, 1999; Brown, 1991; Hahn, 1993; Smart, 2004, 2005a, 2005b, 2006, 2007; Smart & Smart, 2007, Walkup, 2000; Zola, 1993). Nonetheless, most individuals with little or no experience with disability view disability as only physical disabilities, such as orthopedic impairments, amputations or limb deficiencies, or sensory losses such as blindness, deafness, or deaf/blindness. These misconceptions are often perpetuated and reinforced by the popular media, such as movies, books, and television (Bogdan, 1988; Byrd, 1979; Byrd, Byrd, & Allen, 1977; Byrd & Elliot, 1988; Byrd, Williamson, & Byrd, 1986; Kriegel, 1987; Longmore, 1985; Mirzoeff, 1997; Norden, 1994; Safran, 1998; Zola, 1988, 1992). These media tend to focus on presenting only those real-life IWDs who have accomplished remarkable tasks, such as a blind man, Erik Weihenmayer (2001), climbing Mt. Everest; a deaf/blind woman, Helen Keller, becoming a worldwide celebrity (Herman, 1998); or a movie actor, Christopher Reeve, becoming a self-proclaimed public advocate for those with quadriplegia (Reeve, 1998). Obviously, all of these individuals had severe disabilities; but they also had a great many resources to manage their disability, far more than the majority of IWDs. Furthermore, most of the "disabled heroes" developed their skills or celebrity before they acquired a disability. Weihenmayer climbed mountains as a child and teenager; Christopher Reeve was a famous movie actor; and Helen Keller had the remarkable resource of a full-time companion for 47 years, Annie Sullivan (Brueggemann & Burch, 2007). Thinking only of deaf/blind individuals, it is probably true that most IWODs cannot name another deaf/blind individual, other than Helen Keller.

THE UNWARRANTED FEAR THAT IWDs PROVOKE IN IWODs

- Why do IWODs experience existential angst or fear and anxiety about acquiring a disability?
- Most IWDs consider the reaction of IWODs to be the most difficult aspect of living with a disability.

There are medical and biological realities to all disabilities and all disabilities include functional losses and limitations, all require management and control, and many are expensive. However, most IWDs, and their families, state that their greatest difficulty is responding to the prejudice, discrimination, unnecessary limitations, and lowered expectations of the general society (Davis, 1997, 2010; Scotch, 1984). Thus, the greatest barriers for most IWDs are imposed by society. No one seeks to acquire a disability or have a child with a disability; but, on the other hand, many IWDs state that there are positive aspects to the disability, that they are proud of their mastery of the disability, and that the disability experience is not an unending tragedy. For example, according to a Gallup poll, 42% of Americans polled stated that blindness is "the worst thing that can happen" (The Lighthouse, Research to Prevent Blindness, 1995). Blind Americans would probably disagree with the sighted Americans who responded to the poll (The Lighthouse, 1995).

Dr. Geerat Vermeij, an evolutionary biologist and a professor at the University of California at Davis, has been blind since early childhood. In the following excerpt from his book, *Privileged Hands* (1997), Vermeij explained the way in which uninformed and naïve, but widely held, perceptions of blindness contribute to society's fear of blindness:

> Yet opinion polls almost unanimously portray blindness as the most feared of human conditions. Sight is *perceived* as the means by which we gain the bulk of our information about one another and about our surroundings. Accordingly, educators have built curricula almost entirely on a foundation of visual learning. For this reason, blind people are widely regarded as being incapable of learning or interacting fully with others. Skeptics despair that blind people cannot see facial expression, cannot witness a baby's first tentative steps, cannot respond to a smile, cannot see how others behave. Without such quintessentially visual experience, the argument goes, the blind are denied a basic dimension of what it means to be human. Naively, [they] fear or loathe blindness. (p. 16)

Note the way in which Vermeij adds that most sighted people think that blind people are not totally human. How can a person be human if he or she can't see?

Those IWDs who have reached the highest stage of acceptance of disability, called "transcendence" (Vash, 1981), often feel that they are better people because of the disability, wish to assist others with the same type of disability, and feel that they have had opportunities and experiences that would not have been open to them if they did not have the disability.

Perhaps the combination of a lack of knowledge about the disability experience and the uncomfortable feelings that disability arouses in most IWODs result in seeing IWDs as one of two opposites, a hero or a pathetic IWD. Neither stereotype allows the IWD to be seen as an individual and both are extreme roles, prompted by intense discomfort of IWODs (Elliot, Frank, Corcoran, Beardon, & Byrd, 1990).

IWDs often provoke anxiety in IWODs because IWDs remind them of the possibility (and perhaps the probability) of acquiring a disability. Paul Longmore (2003) described this fear: "Disability happens around us more often than we generally recognize or care to notice, and we harbor unspoken anxieties about the possibility of disablement to us, or someone close to us. What we fear, we often stigmatize and shun" (p. 2003). Heinemann and Rawal (2005) stated:

> Spinal cord injury resulting in permanent paralysis and loss of sensation would seem to be one of the most devastating experiences imaginable. Emptying one's bladder with a catheter, using a wheelchair, having difficulty entering one's home and public buildings, being unable to participate in enjoyed activities, and disrupted sexual expression may seem to the outsider like a life not worth living.. . . People who sustain SCI (spinal cord injury) do live independent lives and fulfilling lives. (p. 610)

Kleege is a university professor who is blind, worries about "Normals," and feels like "they need a lot of help."

> I worried about a lot of them so much, the Normals I know. If some of them never became disabled . . . it will be a bad business. If they could just let go of the fear, I think, I have fear, too. I am afraid of losing my hearing. But I know that if or when it happens, I'll make do somehow. Making do is not such a foreign concept to me. For the Normals, making do is dreadful even to contemplate. What would life be without a leg, without eyesight, without hearing, they worry. Life would be life . . . I say. Flawed and limited in some ways, rich and various in others.

> I don't enjoy feeling like we [IWDs] exist to offer illuminating insights to the Normals. But in my more generous moments (few and far between as they are), I feel like it's something worth doing. They [Normals] need a lot of help. (Kleege, 2006, p. 182)

Most IWDs report that the most limiting aspects of the disability have nothing to do with the disability itself; rather, social conditions, such as lack of accommodations and other civil rights, and the inaccurate perceptions of IWODs unnecessarily limit the lives of IWODs (Zola, 1982). Moreover, if "society" has "constructed" these limitations, then it seems logical that society can also "de-construct," or at minimum, greatly reduce these limitations (Higgins, 1992a). Madeline Will (as cited in Weisgerber, 1991), former assistant secretary for education and head of the Office of Special Education and Rehabilitation (OSER), stated:

> Most disabled people . . . will tell you that despite what everything thinks, the disability itself is not what makes everything different. What causes the disabilities is the attitudes society has about being disabled, attitudes that make a disabled person embarrassed, insecure, uncomfortable, dependent. Of course, disabled people rarely talk about the quality of life. But it is has precious little to do with deformity and a great deal to do with society's own defects. (p. 6)

"PEOPLE MEET MY DISABILITY BEFORE THEY MEET ME"

IWDs do not define themselves primarily as individuals with disability nor do IWDs view the disability as the most important part of their self-identity. Rather, the disability is an important part of the individual's identity; but, like everyone else, IWDs define themselves by multiple roles and functions (Antonak, 1985; Fine & Asch, 1988a, 1988b, 1988c; Olkin, 1999). IWODs, in contrast, often view an IWD as the disability, as shown by the words they use—a quad, a schizophrenic, "the blind guy," or "the woman in the wheelchair." Nothing else about the IWD is recognized or acknowledged; the disability is the IWD's "master status." Thus, the IWD is always viewed as the "other" or "someone who is not like us." One woman with a disability explained, "People meet the disability before they meet you" (National Public Radio, 1998, "Inventing the Poster Child") and another IWD stated, "You want to be yourself and the world wants you to be the disability" (National Public Radio, 1998, "Inventing the Poster Child"). IWODs often think that every thought and behavior is a direct result of the IWD's disability, thus ascribing much more importance to the disability than do the individuals who have disabilities.

Nor do IWDs view themselves as "heroes" or "pathetic cripples" and they often resent when IWODs describe them in these two ways. Especially insulting to IWDs is the label of "hero," or judgments such as "I don't how you do it" or "I know I couldn't handle your disability." Occasionally, professionals who work with IWDs are told, "God bless you for doing this work." All of these judgments are well-intentioned, but often insulting and demeaning to those to whom these judgments are addressed, IWDs. These types of perceptions do not allow the IWD to be an ordinary person and communicate to the IWD that he or she is viewed only as the disability. These perceptions are not accurate because most IWODs do not understand the disability experience or the demands in responding to the disability. Viewing the IWD as a pathetic crip, someone who is an object of pity, sympathy, and charity, most often is well-intentioned. Nonetheless, the recipient, the IWD, is

not viewed as a contributor. These false perceptions are illustrated in the accounts of many individuals with a visible physical disability who report that when they were shopping at a mall, strangers tried to give them cash.

THREE BROAD CATEGORIES OF DISABILITIES

- Categorized according to symptoms, not causes
- Three broad categories:
- Physical
- Intellectual
- Psychiatric

Most IWODs would be surprised to learn that the most common disability in the United States is arthritis. Perhaps because arthritis is a chronic illness, the general public does not realize that arthritis is a disability; but individuals with chronic illnesses comprise a large segment of the disability population. Traumatic injuries often result in disabilities, but not always. Following medical stabilization, some individuals are restored to complete functioning but others survive with a lifelong disability.

Categorization of disabilities is most often based on the symptoms and rarely on the causes (Table 1.1). The etiology is the cause of the disability and for many disabilities, the cause is unknown or there are multiple causes. Thus, there are three general categories of disability: physical disabilities, cognitive disabilities, and psychiatric disabilities. Those with physical disabilities exhibit physical symptoms; those with cognitive disabilities experience cognitive symptoms; and those with psychiatric disabilities experience psychiatric symptoms. Nonetheless, if disabilities were categorized by cause, everyone with a disability would have a physical disability because there are physical causes to all types of disabilities, including psychiatric disabilities. Nor does this categorization system always and completely correlate

TABLE 1.1 Prevalence of Disability Among Non-Institutionalized People of All Ages in the United States in 2017

DISABILITY TYPE	%	MOE	NUMBER	MOE	BASE POP.	SAMPLE SIZE
Any disability	12.7	0.05	40,714,800	156,310	321,823,700	3,118,647
Visual	2.3	0.02	7,543,000	71,090	321,823,700	3,118,647
Hearing	3.6	0.03	11,524,400	87,320	321,823,700	3,118,647
Ambulatory	6.9	0.04	20,898,200	115,810	302,104,600	2,955,036
Cognitive	5.1	0.03	15,391,000	100,280	302,104,600	2,955,036
Self-care	2.6	0.02	7,935,500	72,870	302,104,600	2,955,036
Independent living	5.6	0.04	14,592,000	97,770	260,869,300	2,581,685

MOE, margin of error.

Note: Children under the age of 5 were only asked about vision and hearing disabilities. The independent living disability question was only asked of persons aged 16 years old and older.

Source: Erickson, W., Lee, C., & von Schrader, S. (2019). *2017 disability status report: United States*. Ithaca, NY: Cornell University Yang-Tan Institute on Employment and Disability (YTI).

with some large diagnostic manuals. For example, the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5),* published by the American Psychiatric Association (APA, 2013) includes both psychiatric disabilities and cognitive disabilities. This makes sense because psychologists and psychiatrists serve individuals with these who have cognitive or psychiatric disabilities and the *DSM* is published by a professional group and not a government entity.

Physical Disabilities

- Blindness and vision loss
- Hearing loss and deafness
- Dual sensory loss: Deaf/blindness
- Mobility impairments
- Autoimmune diseases
- Cerebral palsy (CP)
- Spina bifida
- Muscular dystrophies
- Chronic illness and health disorders
- Disfigurements

Physical disabilities include mobility impairments, sensory loss, such as blindness or deafness or deaf/blindness; neurologic impairments, such as CP and seizure disorders; traumatic brain injury (TBI); and musculoskeletal conditions, such as muscular dystrophy and arthritis. The diagnosis of physical disabilities is frequently accomplished with the use of standardized, objective, quantifiable laboratory procedures, such as blood tests, magnetic resonance imaging, and x-rays. For many disabilities, there are standardized levels of severity such as mild hearing loss, moderate hearing loss, and severe hearing loss. Each of these levels of severity is based on a specific number of the loss of decibels of hearing (standardized) and different audiologists would arrive at the same diagnosis (objectivity).

Blindness and Vision Loss

Visual impairments include total blindness from birth; the gradual loss of vision, such as retinitis pigmentosa (RP), muscular disorders, such as strabismus, or "crossed eyes," and loss of acuity across the visual field, such as tunnel vision (Rosenthal & Cole, 2005). People who wear eyeglasses or contacts are not considered to have a visual impairment (nor are they protected under the Americans with Disabilities Act [ADA]) because the provision of widely used and easily obtainable adaptive technology (eyeglasses and contacts) restores the individual to full functioning. Indeed, testing for vision loss takes into account the individual's "best corrected vision."

The age distribution of vision loss is different from other types of disabilities (Table 1.2). Blindness and severe vision loss typically occur at the beginning of life (before age 1) or at the end of life. It is estimated that 60% of all visual impairments occur before the age of 1 year. More than 100,000 Americans have RP, a degenerating disability that destroys the center of the retina and for which there is no cure. Most individuals with RP are blind by the age of 40. Relatively speaking, there are few individuals who become blind in middle age. By the year 2030, an estimated 6.3 million Americans will have some form of macular degeneration, which results

TABLE 1.2 Percentage of Americans With Vision Loss by Age

AGE (YEARS)	PERCENTAGE OF AMERICANS WITH VISION LOSS (%)
18–44	7.2 (0.32)
45–64	13.1 (0.41)
65–74	13.4 (0.63)
75 and over	18.9 (0.85)

Source: National Center for Health Statistics. (2017). *Summary health statistics: National Health Interview Survey*. Retrieved from https://ftp.cdc.gov/pub/Health_Statistics/NCHS/NHIS/SHS/2017_SHS_Table_A-6.pdf

in blindness or vision loss (Brain Awareness Week, 2019). Macular degeneration is most common among elderly people.

Another interesting aspect of blindness is that it is considered the disability with the least stigma. The general public, mostly IWODs, typically do not blame individuals for their blindness and, mistakenly, IWODs think that they understand blindness. Finally, blindness is a disability for which there are objective and standardized diagnostic procedures that include measuring visual acuity. The best estimate of the number of Americans (of all ages) with visual impairments is 1.5 million, although disability demographers caution that vision impairments are underreported.

A large percentage of visual impairments have no known cause. Degenerative conditions, affecting the retina or optic nerve including RP, retinal detachment, and glaucoma are common causes. Genetic factors cause vision loss, such as malformation of the eye or blindness, and this may be acquired from infections, accidents, or tumors.

Presently, there are a larger percentage of individuals with vision impairments than ever before in the United States. However, advances in medicine, especially neonatal medicine, have greatly reduced the number of infants born with blindness. The answer to the puzzle is the larger number of elderly people in the American population and vision loss is quite common among the aging. Vision loss is a secondary condition of diabetes, a condition that affects millions of Americans. Macular degeneration, another common disability among older individuals, causes blindness.

Two factors have been eliminated that, in the past, contributed to the high number of infants who were born blind. These two factors are maternal rubella (a pregnant woman contracting German measles) and excess oxygen administered to premature infants, which resulted in retrolental fibroplasias. There is now a rubella vaccine and incubators developed in the 1960s control the amount of oxygen given to infants. However, there are many adults, born before 1960, who are blind because these medical innovations were not available.

Individuals with severe vision loss cannot learn by observation or demonstration and those with congenital blindness have no memory or visual experiences of such concepts as color, distance, depth, or proportion. Falvo (1991) explained:

> [Individuals who have congenital blindness] because of their lack of visual experience in the environment, such as the observation of tasks or behaviors of others . . . must learn by other means concepts that sighted individuals

> often take for grant. This adaptive learning of tasks then becomes a natural part of their developmental process so that the adjustment to visual limitations is incorporated into their self-perception and daily activities as a normal part of growing up. Individuals who lose their vision later in life have the advantage of being able to draw on visual experiences in the environment as a frame of reference for physical concepts, but they may find it more difficult to accept their blindness than those who have never had vision. (p. 255)

Erik Weihenmayer, a blind man who climbed Mt. Everest, became totally blind as a teenager as a result of a degenerating condition. He was a skilled, experienced climber before he became blind. Also, the course of his blindness, gradual degeneration, allowed him time to adapt and accept his eventual blindness. Interestingly, his blindness proved to be an asset on Everest because he was highly skilled at night climbing (which his sighted companions were not) and his keen sense of touch and hearing alerted him to the presence of crevasses. Weihenmayer could "feel" snow which "sounded" hollow. The one adaptation to his blindness that was not available was his well-developed sense of touch because he had to wear gloves. This description of Weihenmayer's assets and compensations does not mean that it is easier to mountain climb when one is blind. It does say that his team of climbing companions assisted him, especially when vision was required; but Weihenmayer also contributed to the climb, using abilities that his sighted companions did not have. Incidentally, one of the greatest contributions Weihenmayer provided his sighted climbing companions was funding and sponsorship. The National Federation of the Blind and the Glaucoma Society funded many of Weihenmayer's climbing expeditions. In the first few pages of Weihenmayer's book, *Touch the Top of the World: A Blind Man's Journey to Climb Farther Than the Eye Can See* (2001), he expresses his need to be a fully contributing member of the Mt. Everest team:

> I refused to be the weak link of the team. I wanted them to put their lives in my hands, as I would put mine in theirs. I would carry my share. I could contribute as any other team member. I would not be carried up the mountain and spiked like a football. If I were to reach the summit, I would reach it with dignity. (p. 5)

Hearing Loss and Deafness

Hearing loss and deafness can be congenital (present at birth) or acquired at a later time. Most deaf infants are born to hearing parents. Individuals with hearing impairments have achieved some degree of recognition and integration within the broader American culture (Moore, 1987; Smart, 2009b). College students are familiar with sign language interpreters in the classroom; we all are able to watch television with closed captioning, and many of us have a grandparent or great grandparent with some degree of hearing impairment (see Figure 1.1).

However, deafness and hearing impairments differ from other types of disability because they bring additional barriers and unique complications: (a) Speech may be impaired, especially in the case of congenital deafness; (b) many individuals with hearing impairments are isolated and are excluded from employment; (c) parents with deaf children must make important decisions about their children's education very early in the child's life, including whether the child will be educated in a community school or a residential school for the deaf and whether the child will learn American Sign Language (ASL) or try to become a speaking person;

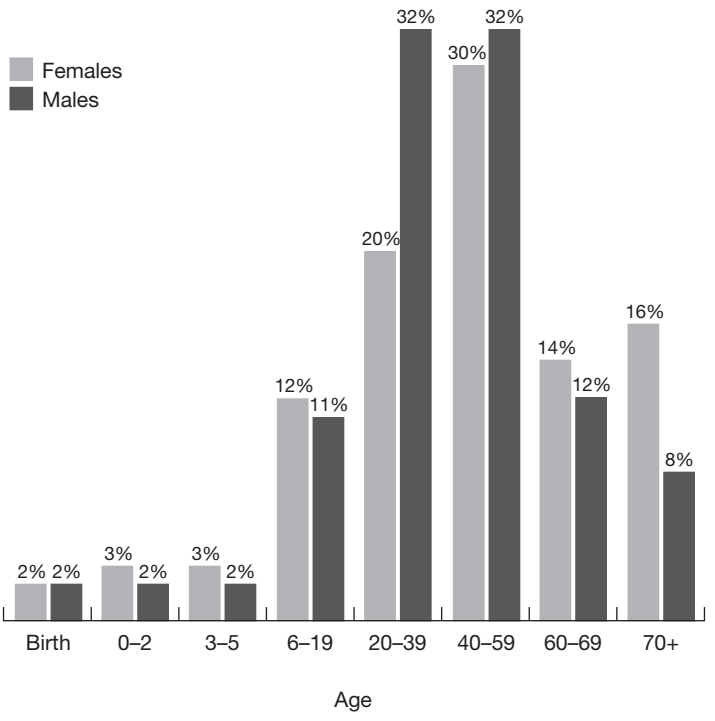

FIGURE 1.1 Age at which hearing loss begins.

Source: National Health Interview Survey. (2007). *Age at which hearing loss begins* (Chart created by the NIDCD Epidemiology and Statistics Program). Retrieved from https://www.nidcd.nih.gov/health/statistics/age-which-hearing-loss-begins

(d) many individuals with severe hearing loss attend residential schools, being required to leave their families and homes at a very young age; and (e) deafness is the only type of disability that is considered, by some, to be a culture with its own language and culture, rather than as a disability, pathology, deviance, or impairment. The Deaf Culture has a long and rich history of providing an environment for deaf people, producing art and literature, and, most especially, advocating for the deaf.

The cause of 25% of all hearing loss is unknown. Hearing loss is measured in decibels and, therefore, the levels of hearing loss are diagnosed using standardized, objective procedures. However, the most important distinction of severe hearing loss/deafness is whether the loss is congenital or acquired later in life. Typically, those with congenital deafness experience great difficulty in learning speech and many never learn speech. Those who experience late-onset deafness cannot hear themselves speak (or anyone else), but they can speak. Congenital hearing loss is often caused by hereditary, genetic factors, such as those that cause otosclerosis and prenatal disease, such as rubella. One expert estimated that 35% to 50% of all cases of congenital deafness are the result of genetic conditions.

Acquired deafness is often caused by postnatal infection, such as scarlet fever, measles, mumps, influenza, typhoid fever, meningitis, or otitis media (ear infections). Helen Keller and her brother had a fever, which was never diagnosed at the

time. It was thought that both children would die; however, Helen's brother died and Helen survived. Helen was both deaf and blind. Obviously, the development of antibiotics has greatly reduced the incidence of deafness from infection. Hearing loss, including deafness, can be caused by environmental factors, such as physical abuse and prolonged exposure to loud noise.

Hearing impairments may become very rare due to a combination of medical and technological advances. Antibiotics cure infections and surgical procedures repair structural anomalies in the ear. Cochlear implants are surgically implanted into the ear (called the cochlea), and provide a small electrical current that stimulates the auditory nerves and provides the sensation of hearing. Other types of technology are available including digital, programmable hearing aids and disposable hearing aids. Hearing aids are programmed to amplify the frequency at which the individual cannot hear. Therefore, hearing aids are custom-designed and programmable.

Dual Sensory Loss: Deaf/Blindness

Helen Keller is perhaps the most famous individual who was deaf and blind. The fact that the general public can name only one deaf/blind individual (Helen Keller) illustrates the low incidence of the disability and the severe communication deficits of deaf/blindness. Before Helen Keller, individuals (including children) who were blind and deaf lived with their families, never attended school, and communicated with gestures. Unlike Helen Keller, they did not attend college, and there were no plays or movies created showing their lives. These other deaf and blind individuals lived in obscurity. As with any low-incidence disability, services and education are very difficult to obtain and there are not many professionals trained to work with individuals with low-incidence disabilities. In addition, children with low-incidence disabilities are typically educated in residential schools.

A biographer of Helen Keller explained the disability of D/deaf-blindness:

> Today, relatively few D/deaf-blind people suffer from Helen Keller's condition—that is, being completely D/deaf and blind from an early age. The life-threatening childhood infections such as meningitis and scarlet fever have been for the most part eradicated, and the simultaneous onset of blindness and D/deafness seldom occurs. (Herman, 1998, p. 340)

Now, almost 50% of all deaf/blind individuals have Usher syndrome, a genetic condition characterized by hearing loss and gradual loss of vision due to a condition called RP, in which the individual begins to experience vision loss in adolescence and gradually loses more and more until middle age, when he or she becomes totally blind.

Mobility Impairments

The category of mobility impairments covers many different types of disabilities, including spina bifida, CP, spinal cord injuries (SCIs), paraplegia; quadriplegia; muscular dystrophy, amputations, including congenital limb deficiencies; and motor neuron diseases, such as Lou Gehrig's disease or muscular dystrophy. Mobility impairments interfere with the individual's movement and coordination and most require some type of assistive technology, such as a cane or a wheelchair.

Most mobility impairments are visible to others and many individuals with mobility impairments experience other disabilities such as hearing loss or an intellectual

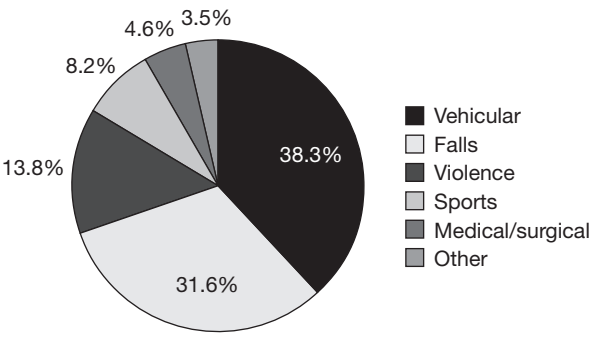

FIGURE 1.2 Causes of spinal cord injury in the United States since 2015.

Source: National Spinal Cord Injury Statistical Center. (2018). *Facts and figures at a glance*. Birmingham: University of Alabama at Birmingham. Retrieved from https://www.nscisc.uab.edu/public_pages/FactsFiguresArchives/Facts%20and%20Figures%20-%202018.pdf

disability. Causes include hereditary genetic causes (muscular dystrophy) or lack of oxygen at birth (CP) or abnormal fetal development (congenital limb deficiency). Trauma causes a significant number of orthopedic impairments, such as SCIs (see Figure 1.2). Eighty percent of all individuals with SCIs are men. This is an interesting statistic; however, the fact that most SCIs are in men means that many treatments and services are often not designed with women in mind. How many women wheelchairs athletes are there? In the following excerpt, note that Herr's primary self-identity is a mountain climber, not an IWD or individual with an amputation.

> Interestingly, the head of the biomechanics group at the Massachusetts Institute of Technology, Hugh Herr, lost both of his legs at age 17 in a mountain climbing accident. In a book named, *Design Meets Disability* (Pullin, 2009), Herr's disability (or better stated, his assistive technology) is considered to be such an advantage that other climbers want to have him disqualified from competitions:
>
> As he came to terms with his disability, his prostheses became an important part of his self-image. But he still thought of himself as a climber, not an amputee. He fashioned himself climbing prostheses that gave him a foothold where others couldn't even gain a fingerhold, and telescopic legs that could be extended during a climb to any length, shorter or longer than his original legs—even each leg a different length. Then he witnessed the reaction of his fellow climbers turn from pity to calls for him to be disqualified from competitive free-climbing for having an unfair advantage. (p. 33)

Autoimmune Diseases

Autoimmune diseases, such as rheumatoid arthritis, often cause mobility impairments. The immune system attacks the joints and slowly destroys them. Women are almost three times as likely to develop rheumatoid arthritis, with ages 20 to 45 as the peak onset years.

Motor neuron diseases include amyotrophic lateral sclerosis (ALS; commonly known as Lou Gehrig's disease); polio, and muscular dystrophy. ALS is a progressive, terminal disease in which the motor neurons degenerate and are replaced with scar tissue. ALS is more common in men and, while it does not affect cognitive or sensory functioning, it results in muscle weakness, including swallowing, speech, and breathing muscles. Age of onset is typically during middle age; 47 is the average age of onset. Most patients die between 2 and 4 years after the onset of symptoms, but 20% live 5 or more years after onset (Bronfin, 2005; National Disability Policy, 2014)

Mobility Impairments

Like many congenital disabilities, there is a wide range of severity in CP. CP occurs when the brain is injured in the fetal period, during the birth process, or in early childhood. Perhaps the most common cause of CP is lack of oxygen (*anoxia*) during the birth process. CP is a lifelong disability because the brain injury is permanent. In mild cases, there are symptoms that are not very visible and in severe cases, there are muscle disorders, such as accuracy of muscle movement, and involuntary movement that are visible. Falvo (1999) described these symptoms: "Some individuals with cerebral palsy have *ataxia* (disorder in the accuracy of muscle movement), which affects their balance and coordination of gait. Still others have *dyskinesia*, involving unwanted, involuntary movement muscle movements. Specific types of dyskinesia include slow writhing; purposeless movements (*choreoathetosis*). Some individuals have a combination of spasticity, ataxia, and dyskinesia." If other parts of the brain are injured, additional problems, such as vision and hearing impairments, or seizures, or intellectual disability result. Experts expect an increase of the incidence of CP as the number of extremely low-birth-weight infants survive. This is not to say that all low-birth-weight babies will have CP (or any other disability). Rather, the probability of CP is greatly increased in these infants and physicians provide respiratory support to the infant,immediately following birth. Also, in utero treatment (treatment given to the fetus in the uterus) can be provided. Twins and triplets and other multiple births have an increased probability of CP because infants in multiple births tend to be of low weight.

Spina bifida is a congenital disorder in which the spinal column has spaces in one or more vertebrae, thus the name: "Bifida" means divided and spina bifida is divided spine. In mild cases, there are few, if any symptoms, while in severe cases, muscle paralysis, loss of sensation, and loss of bowel and bladder control are much more likely. In one type of spina bifida, the membrane surrounding the spinal cord pushes out through an opening in the spinal cord and in another type of this disability, both the membranes and the nerves of the spinal cord push out through the opening. Physicians describe the condition as: "extrusion of abnormally formed neural elements" (Gold, 1996, p. 461). Surgery, or multiple surgeries, is required to repair these defects and to prevent further or permanent damage to the spinal cord. Infants born with spina bifida may also have hydrocephalus (fluid on the brain), which can result in intellectual disability if the fluid is not surgically drained and a shunt placed to continuously drain the fluid as it accumulates. Children and adults with spina bifida are susceptible to infections in their spine and, because of this, they typically experience several hospitalizations each year. Spina bifida is a lifelong disability, with severe impairments in many areas of functioning.

In the last decade, there has been a 27% decrease in the number of infants born with spina bifida, which is attributed to the folic acid supplements added to grain

products, such as cereal. It is important that pregnant women take folic acid because folic acid aids in neural tube development. However, Gold (1996) explained that there are many causes of spina bifida: "Although folic acid supplementation plays a role in prevention, the etiology for neural tube defects is likely multifactorial and has a genetic basis." (p. 463)

Muscular dystrophies (there are several types) are hereditary conditions that are characterized by progressive muscle degeneration. Congenital muscle dystrophy is apparent at birth and, in severe cases, obstetricians and pediatricians must guard against respiratory failure in the newborn. The infant shows weakness and restriction of joint movement (Bronfin, 2005).

There is a large number of causes of mobility impairments, including birth trauma, later-in-life injuries, and degenerating conditions. John Hockenberry, a reporter for National Public Radio and Middle East correspondent, describes the variability in paraplegia and quadriplegia:

> "Paralyzed from the waist down" describes so little of the experiences of a spinal cord injury that most crips use it as kind of shorthand joke. In my case, I am paralyzed from the nipples down. When people learn this they are shocked to realize that there is no international checkpoint at the waist. It is an arbitrary demarcation. In actual fact, relatively few people are paralyzed from the waist down. Everyone has their particular separating sensation from numbness. Each line of separation is invisible to the eye. In some people the aspects of temperature and pressure and muscle control are separate. Some spinal cord injured people can feel pressure but not temperature in some parts of their body and vice versa. There are people with almost total sensation but with no motor control . . . a partially damaged fiber-optic cable . . . picture, but no sound . . . bad reception. All these metaphors aid understanding, but none is precise. The trace of each paraplegic and quadriplegic's sensory border zone is unique as a fingerprint. Each person has a different answer to the question: What does paralysis feel like? (Hockenberry, 1995, p. 97)

Chronic Illness and Health Disorders

We have discussed some chronic illnesses in the section on Mobility Impairments and Autoimmune Diseases. In addition, diabetes, cardiovascular disease, brittle bone disease (osteogenesis imperfecta), rheumatoid arthritis, Parkinson's disease, ankylosing spondylitis, and Huntington's chorea are recognized to be disabilities. All of these conditions limit functioning and are chronic, lifelong conditions and are therefore recognized as disabilities.

- Diabetes is a condition of carbohydrate metabolism that results in an imbalance of the availability of the hormone insulin. Diabetes must be managed on a daily basis and is almost a "gateway" disability because its complications lead to limb amputations, blindness, and other disabilities.
- Cardiovascular disease, because of its limiting, chronic nature and the need for treatment and management, is a disability. The arteries that supply the heart are the most important blood vessels in the body.
- Huntington's chorea (or disease) is a slow, progressive, hereditary disease of the central nervous, which typically is diagnosed in young adulthood. Individuals with Huntington's have jerky, involuntary movements and intellectual

deterioration. Death occurs approximately 15 years after the first onset of symptoms.

- Rheumatoid arthritis is a chronic, progressive systemic disorder in which the joints become inflamed and swell. It is thought to be an autoimmune disease. Autoimmune diseases occur when the body's immune system attacks itself, leading to inflammation and cell death.
- Parkinson's disease is also a slowly progressive disorder of the central nervous system. Characteristics of Parkinson's include involuntary tremors, extreme slowness of movement, and lack of spontaneous movement. The actor Michael J. Fox has Parkinson's and has become an advocate for research and greater awareness of this disease.
- Ankylosing spondylitis is a type of rheumatic disorder which occurs mainly in young men, affecting the joints and ligaments of the spine. It can also affect the hips, ankles, or elbows. Kyphosis (hump back) may result. As with other rheumatic disorders, the joints become inflamed; this causes pain, which often results in fusion of the joints, thus restricting motion.

Disfigurements

Due to advances in surgical techniques, individuals with disfigurements have more options to reduce or remove the disfigurements. Interestingly, disfigurements typically do not include functional limitations, but they are still legally considered to be a disability (Love, Bryne, Roberts, Browne, & Brown, 1987; Macgregor, 1951; Macgregor, Abel, Bryt, Laver, & Weissmann, 1953; Patterson et al., 1993). It is the stigma and other negative responses of society that limit individuals with disfigurements. For example, lower limb amputation (one or both of the legs) is considered to be more functionally impairing while upper limb amputation (one or both of the arms) results in fewer functional limitations. However, upper limb amputation is thought to be a greater disability because of the disfiguring aspects of lacking one or both arms. The majority of disfiguring disabilities have an acute onset, many of them traumatic. For example, individuals who experience severe burns, after medical stabilization, often have lifelong facial disfigurements, although there are no functional limitations.

Cognitive Disabilities

- Intellectual disabilities (IDs; formerly termed "mental retardation")
- Learning disabilities (LDs)
- Developmental disorders—such as autism spectrum disorder (ASD)

Cognitive disabilities include intellectual disability, Down syndrome, LDs, and developmental disorders, such as ASDs. Often traumatic brain injuries are grouped in the broad cognitive category. Cognitive symptoms are impairments in learning, perception, memory, and information processing. These disabilities are grouped together because of their similar symptoms; yet, the range of these symptoms is broad. One aspect of cognitive disabilities that is different from physical disabilities concerns the education and services provided to people with intellectual disabilities. Public, government-funded special education provided in community schools began in the 1960s and employment opportunities before this

time were limited to sheltered workshops. Before the 1960s, most adults with IDs were housed in institutions or simply stayed at home (and many stay home today). Parents who had infants with these types of disabilities were advised by doctors to put their babies into institutions. Many older individuals with IDs were born before the 1960s and have lived their entire lives in institutions. Adult services (the state-federal Vocational Rehabilitation [VR] system) for these individuals were not provided until 1943 in contrast to individual with physical disabilities who received VR services in 1920. In the United States, free, public special education was not available until the 1960s. Some parents of children with IDs organized and provided some education in church or synagogue basements. Often, these parents would hold bake sales or car washes in order to raise funds to buy school supplies.

Therefore, these limitations of individuals with IDs experienced difficulties were not a part of the disability; society created these limitations. It can be said that American society, including government entities, further disabled these individuals by segregating them from society and not educating them (according to their potential). Society made ID smore limiting than necessary.

Intellectual Disabilities

The preferred term is "intellectual disabilities," instead of the stigmatizing label of mental retardation. However, many diagnostic manuals use the diagnosis of mental retardation in very precise, standardized ways, and, therefore, the term "mental retardation" will be used, but only when necessary. An estimated 3% of the American population has an ID, 90% of whom have mild ID (Joseph P. Kennedy, Jr. Foundation, 1991). Severe ID, therefore, is relatively rare. IDs are more than 7 times as prevalent as blindness or deafness and 10 times more prevalent than physical disabilities. While there are standardized and quantifiable levels of severity (mild, moderate, and severe), the diagnostic procedures include paper-and-pencil standardized intelligence testing and clinical impressions. As expected, it is more difficult to diagnose a mild ID than it is to diagnose severe or profound IDs. Frequently, lack of educational and cultural opportunities or lack of English-language skills is difficult to distinguish from a mild ID. Moderate IDs are typically discovered when children enter school and severe and profound IDs are apparent at birth because there are often other disabilities present, such as sensory loss, mobility impairments, seizure disorders or a combination of these disabilities.

ID is defined by the American Association on Intellectual and Development Disabilities (AAIDD; formerly known as the American Association on Intellectual Disability, or AAMR). The AAIDD define ID as "significantly subaverage general intellectual functioning resulting in or associated with concurrent impairments in adaptive behavior, and manifesting during the development period" (Grossman, 1983, p. 1). Social functioning is included in the definition of adaptive functioning (AAIDD, 1992).

In order to distinguish intellectual disability from cognitive disabilities that occur later in life (e.g., senile dementia), this diagnosis is determined in the individual's developmental period, which is birth to 22 years (Drew, Logan, & Hardman, 1992). Individuals with IQs in the range of 55 to 70 would be considered to have mild ID; individuals with IQs in the range of 40 to 54 are considered to have

moderate ID, and individuals with I.Q.s below 40 are considered to have severe ID. The level of adaptive functioning, or better stated, the level of needed support is also taken into consideration.

Most ID is associated with neurological damage. Damage to the central nervous system, typically occurring at birth due to lack of oxygen, abnormal fetal position, or infections often result in IDs. However, some cases of IDs are caused by known organic causes. These include maternal infections, maternal use of alcohol, or incompatible blood types between the mother and the fetus. Changes in metabolic functioning, especially fragile X syndrome, result from genetic-chromosomal factors and often leads to an ID. Down syndrome is caused by a chromosomal defect in the developing fetus. (Dr. Landon Down was the physician who first described Down syndrome.) Many conditions are named for the individual who first described them, such as Alzheimer's, Turner's syndrome, Asperger's syndrome, or Tourette's.

A pediatrician (Batshaw, 2001) made clear distinctions between the terms developmental delay, developmental disability, and mental retardation:

> Physicians used the term *developmental delay* to describe a young child who is slow in developing but has the potential to catch up. This contrasts with the term *mental retardation*, which implies a permanent and significant slowness in development. The term *developmental delay* is often used in describing a premature infant; it is rarely appropriate to be used for a child older than 2-3 years of age. Unfortunately, professionals often use the term *developmental delay* long after it has become clear that the child has mental retardation. It then becomes a way of avoiding the reality that may be painful to the parent and to the professional. (p. 54)

Learning Disabilities

LDs are becoming one of the most often diagnosed disabilities, meaning that the actual rate of LDs may not be increasing as much as it appears, but simply that more and more individuals are being screened and, therefore, there are more frequent diagnoses. Once considered a disability that the individual "outgrew," it is now known to be a lifelong disability.

Diagnosis of an LD first begins by eliminating other possible causes, such as a sensory loss or an intellectual disability (National Disability Policy, 2014). Children with suspected LDs are initially identified because of a discrepancy between their measured academic potential (IQ) and their actual academic performance. The causes of LDs can only be speculated, although functional magnetic resonance imaging has shown that children with LDs have reduced physiological functioning in the cerebellum. Other suspected causes include lack of communication between the hemispheres of the brain or that one hemisphere is larger than the other (termed "asymmetrical development").

Autism Spectrum Disorder

In 1943, Leo Kanner described a group of 11 children who displayed a similar pattern of symptoms that were very different from those of other childhood behavior disorders. Kanner used the term "early infantile autism" to describe the disorder

(Morris, Morris, & White, 2005). "Autism spectrum disorder" is a term created by the APA and is used to describe a pattern of neurologically based impairments in social interactions and communications

According to Morrison (2014),

> Autism spectrum disorder (ASD) is a heterogeneous neurodevelopmental disorder with widely varying degrees and manifestations that has both genetic and environmental causes. Usually recognized in early childhood, it continues through to adult life, though the form may be greatly modified by experience and education. (p. 26)

Deficits in social interaction may be noticed as early as 6 months when parents notice their infant is not making eye contact, is not smiling reciprocally or wanting snuggling, and is displaying no desire for physical closeness. Motor milestones are typically on time for infants with ASD, but it is the type of motor activity that is unusual. Many of these behaviors are termed "stereotyped" or "ritualized" or "inflexible," meaning that there is no observed purpose to these behaviors, other than to reduce stress. Repetitive twirling, twisting, rocking, flapping of the hands, and head banging are example of stereotyped behaviors.

Deficits in communication include total failure to react to others, engaging in repetitive monologues, and lack of body language. Those with ASD often fail to understand abstract meaning, jokes, or sarcasm. Often they ask the same questions to the same people over and over.

Sensory sensitivity often occurs, including avoidance of bright light, loud noises, and rough textured fabrics. While many with ASD experience an intellectual disability, a few individuals have enhanced cognitive skills in a narrow area, such as music, math, and rote memorization; however, these individuals are unable to function independently. Due to all these deficits, ASD is considered a severe disability that greatly affects family life.

The diagnostic criteria of ASD in the *DSM-5* differ from the same diagnosis in the *DSM-IV-TR*. The criteria did not change, only the name of the diagnosis and its categorization. When disabilities are measured on a continuum (or spectrum or dimension), one end of the continuum is low functioning (extreme and severe) and the other end is high functioning. In the case of ASD, Asperger's was the diagnostic label given to individuals with the manifestations of autism, but who function at higher levels and have no language deficits. Typically, those formerly diagnosed as having Asperger's were probably viewed by others as odd, especially in social situations, but they often had remarkable skills and abilities that often led to productive careers. The old joke is that Silicon Valley is full of people with Asperger's. Perhaps due to the Internet, those with Asperger's have a collective positive identity, calling themselves "Aspies," and referring to IWODs in somewhat belittling terms, "neurotypicals." This can be considered a type of "pride" movement.

In contrast to diagnoses based on a continuum, there are diagnoses based on categories. In categorical measurement, diagnoses are considered *qualitatively* different and in diagnoses measured on a continuum, diagnoses are considered *quantitatively* different. Blindness and deafness would be categorical measurement while ASD is measured on a continuum, with diagnoses based on differing levels of severity. Continuum diagnoses are often difficult to make because some type of cut-off point must be determined—what separates medium-functioning ASD from

high-functioning ASD? Where do you draw the line? Also, if service provision is tied to a diagnosis, clinicians may be tempted to "fudge" and render a diagnosis of ASD when the individual did not meet all the criteria.

Another problem with disabilities and diagnoses based on a continuum is that, to the public, individuals with high functioning diagnoses represent the entire continuum. Ask someone to name a person with Asperger's or high functioning ASD and he or she will state Dr. Temple Grandin, but will probably be unable to name anyone else. Nonetheless, there are many individuals with low functioning autism who are unable to communicate, have severe intellectual disabilities and are incontinent and, therefore, are very quantitatively different from Dr. Grandin. One mother of a child with low-functioning ASD expressed this concept:

> Please don't write about them (high-functioning Asperger's) They're a handful of noisy people who get a lot of media attention. They're trivializing what autism really is. It's like stealing money from the tin cup of a blind man when you say that it's not an illness; you are getting the people who should be making political and social change to think that it's not a problem. (Solomon, 2012, p. 280)

This mother realized that whatever group represents the entire continuum (which is not possible) is the group who receives funding, access, and social acceptance.

In the following chapters, we discuss the meaning of diagnoses for the individual and his or her self-identity. In the popular magazine *The Atlantic,* an article about the removal of the diagnosis of Asperger's from the *DSM-5* included an excerpt of someone who felt that his self-identity had been changed without his permission. For John Elder Robison, the revision is an abrupt and unwelcome assault in an all-important identity.

> "Just like that, Asperger's was gone," he wrote in an essay on the *New York Magazine's* website. "You can do things like that when you publish the rules. Like corrupt referees at a rigged college football team, the APA removed Asperger's from the field of play and banished the term to the locker room of psychiatric oblivion." Robison, who grew up feeling under siege in a deeply dysfunctional family in the 1960s, champions the label and tribal protection it offers in a "neurotypical" world that he is sure will always stigmatize and misunderstand people like him—and his son. (Rosin, 2014, para. 1)

Psychiatric Disabilities

- Mental illness
- Mood disorders

Psychiatric disabilities include mental illness, including depression; alcoholism; and chemical and substance abuse. Both the diagnostic criteria and the diagnostic process are based on clinical judgment and the use of paper-and-pencil tests, such as the Minnesota Multiphasic Personality Inventory (MMPI). Of the three disability groups, psychiatric disabilities are most often thought of as to self-inflicted or, at best, disabilities that could have been avoided if the individual simply "tried harder." Psychiatric disabilities are also the disability toward which there is the greatest degree of societal prejudice and discrimination. This prejudice and discrimination is experienced in daily life in social interactions; however, prejudice

and discrimination are also seen in reduced funding for services, unequal insurance coverage, and a very short history of government funding (Mannion, 1996; Marsh, 1992). After all, legislators are subjected to the same societal misperceptions as everyone else. Recent federal legislation is mandating insurance coverage for those with psychiatric disabilities. Also, while the treatment of individuals with any type of disability has been of low quality or nonexistent, the treatment and rehabilitation of individuals with psychiatric disabilities has lagged behind (Orrin, 1997).

Mental Illness

Psychiatric disabilities are diagnosed using the *DSM-5* (APA, 2013). This manual provides information such as diagnostic criteria (those symptoms necessary for the diagnosis to be made), prevalence rates, course of the disorder, and gender features; but the *DSM* does not give treatment plans. The diagnostic criteria are clearly described and, because of this, there is a consistency in diagnosis among various practitioners. The *DSM* is a serial endeavor, meaning that since 1952, there have been many editions (Smart & Smart, 1997). The use of the manual requires specialized training and is typically used by psychiatrists, psychologists, and social workers. While most disorders listed in the *DSM* are defined as disabilities, several disorders such as kleptomania, pyromania, or sexual addiction and other behavioral addictions are not considered to be disabilities and, therefore, individuals with these disorders would not be protected under the Americans with Disabilities Act (ADA) nor would they be eligible for government-funded disability programs, such as VR.

According to the APA (2013), mental illness includes schizophrenia, delusional disorders, bipolar affective disorders, major depression, and anxiety/panic disorders. Many psychiatric disabilities have courses that are episodic, or relapsing, in which symptoms may disappear for a time and then reappear. Relapses or onset of symptoms is called the "active phase" and the disappearance of symptoms is termed "remission."

There is a wide range of subtypes of schizophrenia; however, all of these include distortion of reality and disturbances of thought, speech, and behavior. Schizophrenia affects many areas of functioning and is a lifelong disability. Most cases of schizophrenia begin in late adolescence and early adulthood; although there are a few cases of onset in middle age. Men tend to have experienced an earlier onset (ages 20–24) than women, but women tend to have a more severe form of schizophrenia than men. Schizophrenia is also more prevalent in men, with a ratio of three men with schizophrenia to every two women who develop this disability.

The characteristic symptoms of schizophrenia are delusions, hallucinations, disorganized speech, and bizarre behavior. Hallucinations are sensory experiences that seem real to the individual, but for which there is no external stimulus. "Hearing voices" is an auditory hallucination. Delusions are erroneous beliefs that are firmly held despite clear evidence to the contrary.

Mood disorders, or affective disorders, occur at least 15 to 20 times more frequently than schizophrenia (Butcher, Mineka, & Hooley, 2010). Mood disorders are divided into two broad categories—depressive disorders and bipolar disorders. Affective disorders are not always considered to be disabilities; some government agencies recognize the various types of depression (including bipolar depression) as disabilities and others do not. Those agencies that acknowledge depression to be a psychiatric disability do so because of the pervasive impairment depression causes

in all areas of the individual's life. Falvo (1999) described severe depression as "incapacitation . . . so great that individuals are unable to attend to their own daily needs, such as basic hygiene and nutritional needs" (p. 133). Depression can be fatal since about 10% of those with depression successfully complete suicide. Not all depression is considered to be pathological; for example, grief following the death of a loved one is not considered to be a disorder/disability unless it is unresolved after a lengthy period of time. This is an illustration of the adage, "unpleasant does not mean pathology." In other words, everyone has "down" or "blue" days and, if this were the only manifestation, the individual would not receive a diagnosis of depression. The depressive symptoms must be long term, typically unremitting, and impair the individual's functioning.

The depressive disorders are characterized by some combination of these symptoms, feelings of sadness, hopelessness, decreased energy, feelings of worthlessness and guilt, disturbances in sleep, eating, and activity level, and inability to concentrate. There is considerable overlap in the symptoms of depression and bipolar disorder; however, individuals with bipolar disorder also experience manic episodes in which they have an inflated self-esteem, decreased need for sleep, and become excessively involved in activities, either work or pleasure. It is estimated that between 10% and 50% of individuals with depression will, at some point, have at least one manic episode. Manic episodes tend to begin suddenly. Strictly speaking, depression without manic episodes is termed "unipolar depression" and "correct differentiation" between unipolar and bipolar depression is important (but often difficult) because different treatments are used.

The most frequent age of onset for depression is the early 20s, but depression can be diagnosed in infants, children, and adolescents. Often, individuals are hospitalized in order to stabilize the symptoms. Typically, the more severe depressions have an acute onset (sudden) while the less severe depressions have a gradual (insidious) onset.

Psychiatric disabilities, including mental illness and affective disorders, require lifelong management and there are few total cures. Thus, we can see that psychiatric disabilities parallel physical and cognitive disabilities in that they are chronic, not curable, and require a lifetime of careful management and monitoring. The one difference between psychiatric disabilities and other types of disabilities may be the frequency and intensity of relapses.

UNIQUE DEMANDS OF PSYCHIATRIC DISABILITIES

- Last disability category to be funded, could be the first to be de-funded
- Can build upon the successes of the cross-disability rights movement

Government recognition of disabilities began with physical disabilities, followed by cognitive disabilities, and individuals with psychiatric disabilities were the last category to be considered as eligible to receive resources and services. The history of government recognition of the three broad types of disability parallels the hierarchy of stigma, with the disability group with the least degree of stigma receiving services first, followed by the disability group with more stigma, and finally, the disability group with the greatest degree of stigma receiving government recognition last (Figure 1.3). Those with psychiatric disabilities, and their families,

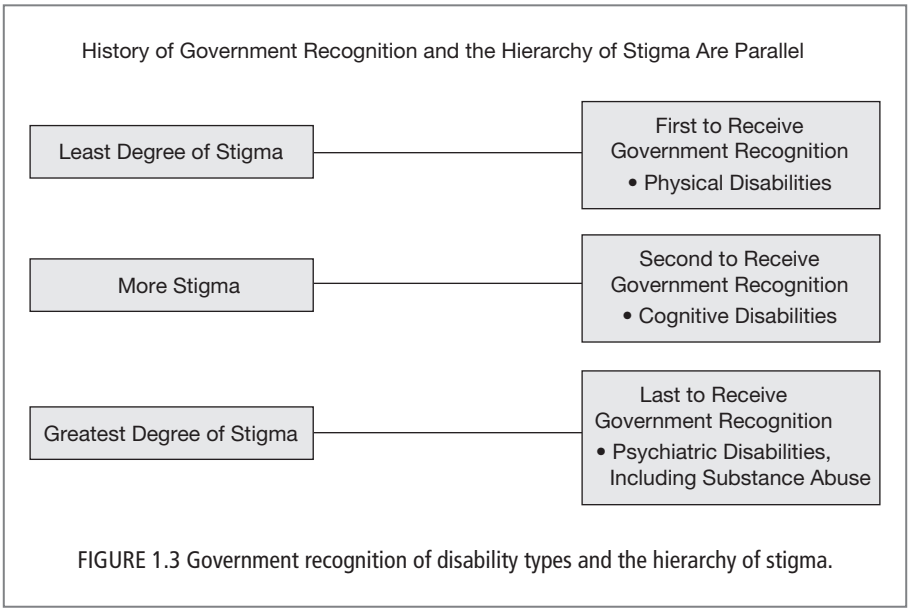

FIGURE 1.3 Government recognition of disability types and the hierarchy of stigma.

worry that in times of economic downturn and a simple re-definition of disability, psychiatric disabilities will no longer be legally recognized as a disability.

Mental illnesses, such as depression and schizophrenia, and chemical and substance abuse are defined as disabilities due to the following factors: They are chronic and lifelong conditions which can be treated and managed, but most are never cured; individuals with psychiatric disabilities are subjected to prejudice and discrimination; and these types of disabilities impair the individual's functioning.

The ADA of 1990 and the Amendments of 2008 have accorded civil rights to a large group of Americans, and many IWDs consider the passage of the ADA to have changed their lives. Some disability scholars believe the greatest achievement of the ADA is the development of a group identity or pride movement that crosses all diagnostic lines. Rather than "the blind" competing with "the mentally ill" for legal protection and resource allocation, a cross-disability focus eliminates this factionalism and advocates for individuals with all types of disabilities. A success for blind individuals is a success for individuals with psychiatric disabilities. As the last recognized disability group, those with psychiatric disabilities can build on the strengths, methods, and achievements of other disability groups.

VIEWING MENTAL ILLNESS AS DISABILITIES

Advantages of viewing psychiatric disabilities as disabilities

- Reduces prejudice and discrimination
- Can be viewed as paralleling other invisible episodic disabilities
- Accommodations, as mandated by the ADA, can be provided, although these accommodations are often not easily understood by others
- Questions of disclosure are difficult because there is a great deal of stigma toward psychiatric disabilities and the invisibility of these disabilities makes nondisclosure possible

Individuals with psychiatric disabilities are subjected to more prejudice and discrimination than individuals with other types of disabilities and part of this stigma is the result of (mistakenly) blaming the individual for the psychiatric disability. While blind people are not blamed for their blindness, psychiatric disabilities are often viewed as moral or character failings. (Blind people are subjected to other kinds of prejudice discrimination, such as lowered expectations and reduced range of choices.) Individuals with psychiatric disabilities are rarely viewed as the moral and legal equivalent of IWODs or of IWDs with physical or cognitive disabilities.

There are many physical disabilities that are invisible and episodic, including various chronic illnesses and the resulting ambiguity often results in increased prejudice and discrimination. For psychiatric disabilities, most of which are invisible and episodic, there is increased stigma due to the invisibility and episodic nature. Ambiguity often makes others fearful, uncomfortable, and stressed, wanting to distance themselves from the source of ambiguity.

Adding to these difficulties, accommodations for individuals with psychiatric disabilities are not as understandable to IWODs as accommodations for IWDs with physical disabilities. Curb cuts, ramps, elevators, and braille signage are easily understood by everyone; however, many accommodations for psychiatric disabilities involve stress reducers such as private offices, flexible work hours, medication breaks, and time off to attend support groups. These often appear to be outrageous demands, rather than as mandated civil rights as Americans under the ADA. One woman with a psychiatric disability reflected on her unnecessary hospitalizations, simply because her requests for medication checks by caregivers were refused. She remarked that no one would withhold a wheelchair for someone with a physical disability, but a daily telephone call to remind her to take her medication was considered to be an inappropriate request.

> When I think about what I had to go through to get those medication reminders, it just infuriates me. I'm a pretty assertive person and in fact, I was on the CMH [Community Mental Health] Board at the time. Yet they said I was trying to be taken care of. That's like saying somebody with a physical disability is asking to be taken care if she needs a wheelchair. No, a wheelchair is a tool or instrument that enables her to have an independent life. My medication calls were my tool and were extremely cost-effective: two one-minute phone calls a day compared to two months of hospitalization. (Mackelprang & Salsgiver, 1999, p. 316)

Individuals with all types of visible disabilities are not faced with the choice to disclose the disability to others because everyone sees the disability or the assistive technology. Those with invisible disabilities have the choice to disclose, including to whom, the timing, and the amount of disclosure. Failing to disclose any type of invisible disability is often termed "passing." When anyone, for any reason, feels compelled to hide an important part of his or her self-identity, cognitive dissonance results and they pay an emotional price. Also, they often become anxious, afraid that their disability will be disclosed or that others will "assume the worse."

Individuals with psychiatric disabilities experience more prejudice and discrimination than those with other types of disabilities and therefore, disclosure often is very emotionally and financially costly. For example, diabetes is an invisible physical disability and, therefore, the individual has the choice to disclose or not to disclose. However, there is little societal stigma toward individuals with diabetes in

contrast to the greater stigma directed toward psychiatric disabilities. Most individuals with psychiatric disabilities struggle with the decision to disclose or whether to "pass" as not having a disability. Disclosure for those with diabetes does not have as many consequences.

Often, IWDs simply want to avoid the "disabled role" of inferiority and deviance. Avoiding the societal-imposed disability role is regarded as an advantage for nondisclosure. Nonetheless, many IWDs with invisible disabilities state that disclosure has many benefits and certainly outweigh the costs. Costs of nondisclosure include the cognitive dissonance and discomfort of pretending to be nondisabled, constant fear of being discovered, and without disclosure, there are no accommodations provided.

INDIVIDUALS WITH PSYCHIATRIC DISABILITIES EXPERIENCE PREJUDICE AND DISCRIMINATION

A constellation of factors lead to more prejudice and discrimination than experienced by other disability groups

- Ambiguity, even among professional caregivers
- Individuals with psychiatric disabilities are often thought to have caused their disability
- Individuals with psychiatric disabilities are often held responsible for their "cure"
- Accommodations are difficult to understand

A psychiatrist/researcher/author, Joel Paris (2015) described situations in which professionals have held individuals with psychiatric disabilities responsible for their own problems, which often resulted in lack of medical care.

> I have heard them [emergency department doctors] say, "I am already busy with so many people who are sick for no fault of their own, so why should I have to spend time treating patients whose illness is self-inflicted?" What these professionals are missing is that these patients experience intense suffering, which they express through impulsive actions. (p. 14)

Blaming IWDs for their disability is often a type of subconscious defense mechanism to avoid existential angst. Their reasoning (or feeling) goes something like this, "Well, I will never allow stress to overwhelm me," or "Well, I'll never attempt suicide," or "I'll never drive drunk."

Additionally, when IWODs, consciously or unconsciously, believe that the IWD caused the psychiatric disability, either by doing something or failing to do something, there is an increased tendency for IWODs to engage in the "Try Harder" syndrome. Due to the fact that those with psychiatric disabilities are often thought to have caused their disabilities or that their disabilities are simply moral and character failings, they are often told to "try harder" or given advice on how to "get better," or "just make up your mind to be happy."

Edwina, a young girl in the United Kingdom with degenerating vision, was told by her mother, "You see only what you want to see." Although Edwina had a physical disability, she was chastised for lacking the motivation to see. Even as a young child, Edwina knew that her mother was wrong. Trying harder is not possible when the individual does have the capability.

In the following excerpt, it is easy to see how mental illness may be viewed as laziness or lack of will. Patricia Deegan described her overwhelming reaction to her psychiatric disability and to many it may appear an easy task to get up off the couch. In this excerpt, she speaks of another resident and herself.

> We both gave up. Giving up was the solution for us. It numbed the pain of our despair because we stopped asking "Why?" and "How will I go on?" . . . Giving up meant that for 14 years he sat in the day rooms of the institutions gazing at soap operas, watching others live their lives. For months, I sat in a chair in my family's living room, smoking cigarettes and waiting until it was 8:00 p.m. so that I could go back to bed. At this time, even the simplest of tasks were overwhelming. I remember being asked to come in to the kitchen to help knead some bread dough. I got up, went in to the kitchen and looked at the dough for what seemed to be an eternity. Then I walked back to my chair and wept. The task seemed too overwhelming to me. (1991, p. 49)

Dr. Paris (2015) summarized what he considered the "main cause of stigma associated with mental disorders."

> . . . the fear of losing control of one's mind is the main cause for the stigma of associated with mental disorders.. . . When disorders are exaggerations of normal traits, we recognize ourselves, albeit in a distorting mirror. (pp. 13–14)

In the following chapters, the fear and anxiety of the possibility of acquiring a disability felt by many IWODs has been termed "existential angst." In the case of psychiatric disabilities, IWODs may feel greater fear and anxiety because they perceive the losses of psychiatric disabilities to be much greater than the losses of physical disabilities or cognitive disabilities.

WHY CATEGORIZE DISABILITIES?

Categorization of disabilities in some circumstances often is totally irrelevant in many others. Government agencies are required to develop some system of counting and data collection about disability in order to ensure government services and funding. Advocacy groups need information on disabilities in order to pursue their legislative and public interests. For example, the Muscular Dystrophy Association, a nonprofit organization, probably does not have funds to collect national data on the incidence of muscular dystrophy. Therefore, in order to provide funding and services, it is both ethical and logical to categorize disabilities. When accessing various large-scale systems, such as the U.S. Census, it is important to first understand the way in which disability is being defined before looking at the numbers. For example, some systems include only "activity limitations" or "work limitations," and other systems have a much broader definition and, therefore, the number of IWDs will be higher.

Categorization of disabilities often is not relevant and may even be harmful. Here is a list of the ways in which categorization is not useful:

- Many individuals have more than one disability, such as a physical disability and a psychiatric disability. One category, then, would not describe their experience.

- Categorization of disability exerts a powerful influence on the degree of stigma directed toward IWDs. Broadly speaking, there is a great deal more prejudice and discrimination toward psychiatric disabilities than there is toward physical disabilities.
- Any categorization system lumps a great diversity of individuals, experiences, and needs in a single group which can erroneously lead to stereotypes, such as "all individuals who have an amputation also have a cognitive disability."
- Disability rights advocates support the "cross-disability" perspective. Rather than having organizations for different disabilities competing with each other for resources and civil rights, it makes more sense to include individuals with all types of disability, or to utilize the "cross-disability" perspective (Fleischer & Zames, 2001). IWDs are developing a "collective identity." In fact, if IWDs can be considered a "minority group," they would outnumber any of the racial/ethnic minority groups.

There are biological and physical components of all disabilities and it is important to understand the number of individuals affected by each type of disability. Therefore, in this book, we occasionally use this categorization of physical, cognitive, and psychiatric disabilities. However, the majority of this book views the disability experience and IWDs as including all types of disabilities.

THE INCREASING RATES OF DISABILITY

There are more IWDs than ever before in history. Indeed, the U.S. Census found that 18% of the American population has a disability of some sort. Furthermore, this percentage is probably an underestimation. It is safe to state that everyone will either have a disability, marry someone with a disability, attend school with friends with disabilities, have a baby with a congenital disability, or work with colleagues who have disabilities. The combination of the civil rights bill for IWDs, the ADA, and the increasing rates of disabilities ensure that IWDs will no longer be hidden and segregated from the broader society (Rehabilitation Act, 1973). Moreover, the integration of IWDs into society will enrich and broaden American life.

- Advances in neonatal medicine
- Advances in emergency medicine
- The aging population
- IWDs are living longer
- The liberalization and expansion of the definition of disability
- Greater accuracy in counting

A review of the causes of these increased rates of disability reveals that a higher standard of living results in more disabilities. Included in the higher standard of living are better nutrition, more insurance coverage, greater workplace safety, public sanitation, and wider access to medical care (Smart, 2009a, 2009b, 2009c, 2009d, 2009e). This may appear to be incongruous at first. There are six reasons why there are more disabilities; four are due to medicine and scientific advances and two are termed "statistical" causes, meaning that refined diagnostic techniques and more accurate counting methods have simply found more IWDs.

In many ways, the increasing numbers of IWDs parallel the increasing numbers of elderly people. Such parallels include some of the causes, such as scientific and medical advances and the higher standard of living. The lack of societal opportunity structures available to these greater numbers of IWDs also mirrors the experience

of the elderly. This is termed a "structural lag" (Freund, Nikitin, & Ritter, 2009), meaning that governments and societies often do not keep up with demographic changes. However, the "general public" is more aware of the increasing number of elderly people than they are of the increasing number of IWDs. One indication of this greater awareness is the well-known phrase, "the graying of the population."

Advances in Neonatal Medicine

There are more congenital disabilities (disabilities present at birth) than ever before because of scientific advances in neonatal medicine. Indeed, neonatal medicine is a relatively new specialty of medicine. Neonatal medicine concerns itself with the treatment of newborn (neonates), including fetuses before birth. More infants survive and the infant mortality (death) rate has decreased markedly; but many of these infants survive with a disability. This relationship may be stated in this way: Infant mortality rates are inversely correlated with the rate of congenital disabilities.

Presently, it is commonplace for infants as small as 1.5 lb to survive, and premature and other low-birth-weight newborns have a much higher risk of congenital disabilities. Most premature infants develop well, without complications or disabilities. However, premature babies have a much high probability of developing cognitive, physical, and behavioral disabilities. A premature birth is any birth that occurs before the 37th week of pregnancy (Glass, 2001). These "kilogram babies" often have problems related to their undeveloped organs. Premature infants are susceptible to brain hemorrhage. Societal conditions contribute to low-birth-weight newborns, including births to teenage mothers; worldwide, 1 in 10 babies are born premature (Neergaard, 2009). Neergaard reported that the two areas with the highest percentages of premature births are Africa and North America. She explained that more than 13 million babies are born prematurely each year, and that there are many factors that contribute to prematurity in both wealthy and poor nations. However, only wealthy nations have the high-tech NICUs to care for babies born extremely prematurely. Success stories from these nations create "headlines about miracle babies and . . . a false sense that modern medicine conquers prematurity—without acknowledging lifelong problems including cerebral palsy, blindness, and learning disabilities that often plague survivors" (Neergaard, 2009).

Teenage mothers have higher rates of babies who are premature or low-birth-weight (Himmelstein, Woolhandler, & Wolfe, 1992). Fertility treatments are becoming more common and these treatments have a higher rate of multiple births. There is a much higher rate of congenital disability in multiple births, such as twins or triplets. For example, there is a fourfold increase in the probability of a newborn having CP if the infant is part of a multiple birth. Before 1957, there were no surviving children with spina bifida, although there were infants *born* with this condition. However, all spina bifida babies died a few days after their birth. In 1957, a shunt was developed which drained fluid from the brain of infants with spina bifida, helping babies with severe cases of spina bifida survive (Stefan, 2001). Today, there are relatively high rates of survival of babies with congenital disabilities of CP, Down syndrome, intellectual disability, and spina bifida.

A cause of congenital disabilities that is completely avoidable and therefore would not be considered progress is lack of insurance coverage. When a nation experiences an economic depression or recession, insurance coverage decreases, mostly as a result of job loss and the loss of employer-based insurance (Abelson, 2010).

Lack of insurance is associated with greater numbers of congenital disabilities and more late-onset disabilities. When pregnant women cannot afford prenatal care, there are more congenital disabilities. Also, when middle-aged people cannot afford routine, preventive checkups, diabetes and other asymptomatic disabilities develop.

Advances in Emergency Medicine

The death rate from accidents and other types of trauma has been greatly reduced due to the development of emergency medicine and trauma care. The Vietnam War was the impetus that spurred the advances in emergency care at the scene of the trauma. It is interesting to note that many medical advances were a direct result of military innovations in time of war. The American military in Vietnam used helicopters to transport injured soldiers, evacuating them quickly, treating and stabilizing them while being transported to the hospital. These methods were quickly adopted in the civilian population. Before the Vietnam War, most ambulances carried no medical equipment and only provided transportation. Now fewer individuals die before they reach the hospital, not only in combat, but in civilian life as well. Presently, the death rate from accidents has declined dramatically while the disability rate as a result of injuries, accidents, and trauma has increased. For example, "in 1980, less than 10% of individuals with trauma brain injury (TBI) or spinal cord injuries (SCI) survived; today the survival rate for these individuals with these disabilities is higher than 90%" (Smart, 2009d, p. 39).

Therefore, there are many individuals with SCI, including quadriplegia (paralysis of all four limbs). However, individuals with any kind of paralysis experience many secondary health conditions, such as decubitus ulcers or pressure sores, and respiratory and bladder infections. The use of antibiotics has allowed those with paralysis to live a much longer lifespan (Crewe, 1993). After World War I, there were only 400 American men with battle injuries that paralyzed them from the waist down. Ninety percent of the men with these injuries died before reaching home as a consequence of secondary infections, such as pneumonia. After World War II, and the discovery of antibiotics, there were 2,000 veterans with paraplegia (paralysis of the legs) and 85% were alive 20 years later (Shapiro, 1993). Most individuals with paralysis consider themselves to be healthy, controlling their secondary conditions with antibiotics. Of course, individuals with paraplegia or quadriplegia do not live as long as those without disabilities. Therefore, if young when injured, these individuals can plan for education, employment, and family life. Wheelchair sports illustrate the good health of many of those with orthopedic impairments.

TBI is an acquired damage to the brain, which alters functional capacities such as motor control, sensation, perception, cognition, memory, personality, and emotion. TBI is a lifelong disability with pervasive limitations of motor abilities, cognitive abilities, and changes in personality. There are levels of severity, including mild, moderate, and severe. Due to the fact that mild TBIs frequently do not result in impairments, it is thought that the incidence of TBI is underreported. The Centers for Disease Control and Prevention (CDC) estimates that approximately 1.5 million people acquire a TBI. Dixon, Layton, and Shaw (2005) explained the relationship between medical advances and the increase in TBIs:

> The rate of survival from TBI has increased over the last 20 years due to advances in emergency medicine, neurosurgery, and intensive care. As a result, the cumulative number of people with TBI is increasing. Many people who

> formerly would have died as a result of accidents or assaults now are saved in the acute period following injury. (p. 120)

Typically, individuals (mostly males) who are between the ages of 15 and 24 have the highest rates of TBI; after age 24, the risk of sustaining a TBI decreases dramatically and after the age of 75, the risk again increases because elderly people tend to fall. Alcohol is frequently associated with accidents that result in TBI. Corrigan (1995) found a 36% to 51% occurrence of intoxication at the time of injury.

Therefore, the combination of (a) the growing survival rates of individuals with TBI; (b) that fact that TBI is a severe disability which limits many areas of functioning; and (c) that it is a disability which typically occurs in the late adolescent years and the early 20s, results in a fairly large group of individuals with TBIs who will progress through most of the lifespan developmental stages.

Aging of the Population

Rate of disability is positively correlated with age. As individuals age, they experience a greater probability of acquiring a disability. Old age and disability are highly correlated. This correlation holds true on an individual basis and for large groups of people. Therefore, nations that have "graying" populations will have higher rates of disabilities and those nations with young populations will have lower rates. Medicine and medical technology have lengthened the lifespan. Arthritis, diabetes, mobility impairments, and sensory impairments (vision and hearing) are disabilities often associated with the elderly. The following are some examples of the way in which the longevity revolution has increased the rate of disability.

- Of all the therapeutic amputations performed in the United States today, 75% are performed on people older than the age of 65, mostly as a secondary condition of diabetes.
- Since the 1970s, stroke mortality rates have decreased, but the incidence of stroke has not decreased. This means that more individuals are surviving strokes, many with disabilities, and most of those who experience strokes are elderly (although younger people can have strokes).
- The prevalence of vision impairments is increasing dramatically due to the aging population. For example, 17% of Americans in the age group 65 to 74 years have a vision impairment and 26% of Americans who are 75 or older have a vision impairment. Vision impairment is diagnosed when the best vision, with eyeglasses or contacts, falls below a certain threshold (The Lighthouse, National Survey on Vision Loss, 1995).
- Individuals with diabetes have a 25 times greater risk for blindness than the general population (Rosenthal & Cole, 2005).

People With Disabilities Are Living Longer

The longevity revolution has allowed IWDs to live longer, although not as long as those who do not have disabilities. So, as the rates of congenital and acquired disabilities continue to rise, the lifespans of these individuals are lengthened. Nearly 90% of children with disabilities survive into adulthood (Jones, Stanford, & Bell, 1997; Lublin & Larsen, 1998, 2006; White & Lublin, 1998). In the past, parents of children with congenital disabilities, such as CP, Down syndrome, or intellectual

disability, were told "take your baby home and enjoy him or her. You won't have this baby for long."

Children with Down syndrome (a genetic condition that causes intellectual disability) are living twice as long today as they did 20 years earlier. In 1983, the average lifespan of an individual with Down syndrome was 25 years and in 2007, the lifespan was 56 years; moreover, the lifespan for these individuals is expected to increase further. This increase is due to advances in surgery and the use of antibiotics (Smart, 2001, 2009d).

These increased lifespans will create the need for more and varied programs for IWDs, especially gerontological programs, and will require medical practitioners to enlarge their scope of practice to include skills in treating various types of disabilities in individuals with a wide range of developmental stages. In the example of Down syndrome, sex and marriage education will become important services to provide to individuals with this syndrome. More importantly, the experience of disability will be different for the individual and his or her family (Sutkin, 1984). Harriet McBryde Johnson (2003, 2005) was a disability rights lawyer who died in 2009 at age 51. She was born with a degenerative muscle disease and her parents were told that she would die in early childhood. In an article entitled "Too Late to Die Young," she explained her response to living past the time that doctors predicted that she would die.

> The death sentence hangs over my childhood like a cloud.. . . As my body continues to deteriorate, my life looks more and more like normal. At 25 I leave the cozy comfort of home to go to law school. I figure I'll be 27 when I finish; if I go now I can probably practice law for a couple of years. By this time, the thought is almost subconscious: when I die I might as well die a lawyer. (p. 44)

Johnson (2005) concluded: "My plan to die young hasn't worked out.. . . It's too late to die young" (p. 46).

The next two causes of increasing rates of disability are termed "statistical causes," meaning that the actual number of IWDs did not increase; rather the way in which disability is defined and counted has changed.

Liberalization and Expansion of the Definition of Disability

Not very long ago, all disabilities were physical disabilities. Disabilities such as LDs, mental illness, and alcoholism were not thought to be disabilities and the individuals who experienced these services were not eligible for government services or funding. After 1990, and the passage of the ADA, individuals who do not have a documented disability as defined by the ADA would not be protected under the ADA. The old adage is, "If you don't have a label, you don't get services" is true. More recently defined as disabilities are AIDS, post-polio syndrome, and chronic fatigue syndrome.

LDs provide an illustration of the liberalization of the definition of disability and the ways in which such liberalization results in decreased stigma from the general public and allows for accommodations and services (Cruickshank, 1990). Children, usually boys, with LDs were thought to be stupid, lazy, and oppositional. Often, their family experienced stigma because schoolteachers felt that the family did not value education. Instead, these children had central nervous system

impairments, which are now beginning to be seen in magnetic resonance imaging. Butcher et al. (2010) explained:

> It is unfortunately the case that LD, despite its having been recognized as a distinct and rather common type of disorder for more than 40 years, and despite its having generated a voluminous research literature, still fails to be accorded the status it deserves in many school jurisdictions. Instead, many classroom teachers and school administrators resort to blaming the victims and attributing the affected child's to various character deficiencies . . . a youngster who learns academic skills slowly or in a different way is treated as a troublemaker.. . . Thus even when LD difficulties are no longer a significant impediment, an individual may bear, into maturity and beyond, the scars of many painful school-related episodes of failure. (p. 551)

These painful episodes result in poor self-concepts. If powerful and authoritative individuals, such as teachers, tell a child something, the child often believes it. John R. Horner described his self-image:

> Back in the days when I was growing up, nobody knew what dyslexia (a type of LD) was.. . . So everybody thought you were lazy or stupid or both. And I didn't think I was, but I wasn't sure. (West, 1994, p. 344)

Horner flunked out of the University of Montana six times, but later "his brilliant synthesis of evidence . . . forced paleontologists to revise their ideas about dinosaur behavior, physiology, and evolution" (West, 1994, p. 334).

When large-scale screenings are used, more disabilities are discovered. For example, in elementary schools, there are screening tests for both hearing and vision. In many hospitals, simple hearing tests are given to all newborn babies. Frequently, there are announcements for screening for depression at universities. Screening tests discover individuals who might (or might not) have the particular disability and send these individuals for further diagnostic testing by highly skilled professionals.

Different government agencies define disability differently (LaPlante, 1991, 1993, 1996, 1997). For example, some agencies include affective disorders, such as depression, in their definition of mental illness and other agencies do not consider affective disorders to be a mental disorder. Those agencies that define mental illness more broadly will report higher rates of the disability of mental illness. Some government agencies only include "work limitations," thus eliminating children and elderly IWDs.

Overdiagnosis, however, is a negative aspect to broadening the definition of disability. For example, there is some disagreement over the incidence of autism, the fastest growing disability in the United States. Indeed, some have termed the large number of newly diagnosed autism cases to be an "epidemic." Autism is a childhood developmental disorder that involves a wide range (or "spectrum") of deficits, such as language, motor, and social skills. Some experts assert that autism is overdiagnosed due to the fact that a child must have a diagnosis (or a "documented disability") in order to be eligible for services and accommodations. Therefore, children with fairly mild impairments may be diagnosed as autistic, because physicians and psychologists understand that the child must have a disability and autism seems to "fit" the child's problems best.

More Accurate Counting

There is a difference between the number of disabilities and the number of *reported* disabilities. Smart (2016) explained:

> As both the general public and government policymakers become clearer on the definitions of disability, the numbers of all individuals *reported* to have disabilities continues to climb. Essentially, more accurate counting is another "statistical" cause for the higher disability rates, because the number of IWDs did not increase, only the number of people who are counted or reported to as having a disability. Furthermore, disability and health demographers consider the reported number of disabilities to be an underestimation, simply because there are many individuals who do not wish to identify themselves as having a disability. (p. 41)

In the same way that the profession and academic discipline of gerontology was a result of the growing number of elderly people, perhaps a new profession and academic discipline will emerge as a result of the growing number of IWDs.

The combination of longer lifespans in IWDs and the liberalization of the definition of disability will serve as an impetus for developmental psychologists to consider the developmental stages and transitions of IWDs. For example, the first generation of adults who were formally diagnosed with LDs as children and (hopefully) received services and accommodations can reflect on their experiences and, in so doing, help parents, teachers, and other professionals to provide sensitive, supportive, and effective services (McNulty, 2003).

With these increasing numbers of IWDs, societal perceptions of disability will change (Linton, 1998). For example, in the future, the use of hearing aids will not be viewed any differently than the use of eyeglasses. There is little, if any, stigma in wearing eyeglasses; however, those who need hearing aids often refuse to use them because they know that this type of sensory adaptive technology can be stigmatizing.

The DSM-5

Large medical and psychiatric diagnostic manuals continue to expand with more and more disorders. It should be noted that not all of these disorders are considered to be disabilities. The fourth edition of the *Diagnostic and Statistical Manual (DSM-IV)* (2000) listed 120 more diagnoses than did the third edition of the *DSM*. For example, LDs were lumped under a single category of "dyslexia." In the *DSM-IV-TR*, LDs are divided into three categories, dyslexia (impairment in reading), dyscalculia (impairment in math), and dysgraphia (impairment in writing.) Asperger's syndrome was not added to the *DSM-IV* until 1994 (APA, 1994). In the *DSM-5*, published in 2013, the definition of learning disorders has been expanded to include specific learning disorders. By expanding the number of diagnostic codes for a broad group of disorders, greater diagnostic precision is possible; however, such expansions have resulted in an ever-increasing number of diagnoses.

While every edition of the *DSM* is a revision, all of the previous revisions have been small, what the *DSM* terms "incremental changes." In contrast, the *DSM-5*, according to the APA, is the most radical revision to date (large changes), taking 14 years to compile. No diagnostic manual is completely free of error nor is every

diagnostic manual totally inclusive, meaning that there may be a few diagnoses that are not found in the *DSM*. The fifth edition is considered to be atheoretical, meaning that possible causes of these disorders are not considered. The first edition (1952) was not atheoretical, but was based on Freud's theory.

The *DSM-5* (APA, 2013) uses a new organization, reflecting its stated change of a focus to a developmental perspective. Chapters are now arranged from disorders diagnosed at birth to diagnoses diagnosed in old age, reflecting the developmental lifespan. Therefore, the first chapter covers Neurodevelopmental Disorders, because these disorders are typically diagnosed in the developmental stages, and the final chapter is entitled Neurocognitive Disorders, because these are usually diagnosed in older people. The five axes system has been eliminated. According to Dailey, Gill, Karl, and Minton (2014), "One of the most far reaching structural modifications of the *DSM-5* is the removal of the multiaxial system" (p. 12). (Axis I was Clinical Disorders; Axis II included Personality Disorders and Intellectual Disability; Axis III includes General Medical Conditions; Axis IV was Psychosocial and Environmental Stressors; and Axis V was The GAF.)

The GAF or the assessment of the individual's Global Assessment of Functioning, has been deleted perhaps due to the great subjectivity in judging overall functioning. Terminology used for some disorders has changed; for example, intellectual disability has replaced mental retardation; illness anxiety disorder has replaced hypochondriasis; and childhood-onset fluency disorder has replaced the term "stuttering."

Perhaps the greatest change in the *DSM-5* is the lowering of diagnostic thresholds, thus increasing the number of individuals diagnosed with psychiatric and cognitive disorders. Examples of lowering diagnostic thresholds are reducing the number of diagnostic criteria in order to make a diagnosis, decreasing the time duration for these symptoms to be present, and in one specific diagnosis, posttraumatic stress disorder (PTSD), diagnoses may be given to individuals who did not experience the trauma, but are family members of someone who did observe or experience trauma out of the normal range of human experience.

DO WE WANT MORE IWDs?

Do we want to have more IWDs? The answer is "yes," and "no." Yes, we want more IWDs when the alternative would be death or lack of services. No, we do not want more IWDs when these disabilities are a result of or are related to societal conditions (such as lack of prenatal care or lack of workplace safety standards). Also, society does want more disabilities if the disabilities could be avoided.

Let us turn to the "no" part of the answer. There are many widely disseminated disability prevention and reduction programs, including the use of seat belts, helmets, and other recreational and workplace safety equipment (Nagi, 1991). These programs are geared at avoiding a disability altogether. However, accidents and injuries do occur and, in these cases, disability is preferable to death. Other disability prevention programs include government-funded access to prenatal care for pregnant women and free or low cost screening programs to "catch" the early onset of diabetes, high blood pressure, and other "silent" (asymptomatic or subclinical) conditions that can lead to further disability. Programs for the prevention of disability or reduction in the severity of disabilities and early diagnosis save money—for